

Session 5
Victor Wahlström
Sweden

Where to Live And How to Live

If one of you were asked the question "Where To Live"? without thinking about the retarded, you would probably answer about like this: During childhood one lives at home, and when one is about twenty, one moves to a home of one's own. If you were to ask the Swedish retarded and their parents the question, "Where To Live?" you would get this answer: During childhood the retarded should live at home with their families. But if the parents for some reason are not able, then one should live in another private home, at least during pre-school years. The alternative to life in a private home of some type is group homes in groups of four.

When one is about 20 years old, one should, if possible, move to a home of one's own, and if not, to a group home of four.

For both children and adults, group homes should be placed in normal neighbourhoods with two groups at the most in the vicinity. This is important, for if the concentration was higher, the retarded would have a hard time melting into the environment.

For the same reason it is important that group dwellings be placed in normal apartments and houses. Both the retarded and

parents believe that this principle of small groups, should also be applied to people with severe or profound retardation. In cases where special medical attention or therapy is needed, this is better handled within the health care sector (for medical attention) and within the psychiatric sector (in terms of therapy and care of the difficult and asocial). But the need for this kind of attention is often only temporary, which means that after a time, the retarded person can return to regular living situations.

Thus, we feel **that no** new large institutions should be planned and that plans be made **to** gradually phase **out** present large institutions. During the phase out period the goal should be that every retarded who so wishes may live in his own room, and that measures be taken to minimize the institutional atmosphere at large care facilities.

Please note that life in institutions is not an alternative answer to the question "Where to Live" for either you or for the retarded and their parents. The point of departure for the retarded and their families is that they should be able to live like everyone else.

How do I know that the retarded and their parents think this way? Well, I base my answer on a new statement of the Swedish National Association for Mentally Retarded (where two retarded are represented), on my own contacts with the retarded and families, and upon several studies of the situation.

First, the retarded themselves. There we have done research with retarded in their own homes and also with retarded in integrated group homes of different types. Early next year we will be able to present the results of a "discussion program" about dwelling conditions which is carried out this fall with about 400 different groups that have an average of 5 retarded people each. This is done on the initiative of the Committee on Provisions which is mandated with overseeing the Law on Provisions which regulates the rights of the retarded in Sweden. These discussions are held in response to a report which mapped out and evaluated the quality of care, where the committee noted that it was self-evident that the opinions of the retarded themselves should also be consulted.

The aim of this material is in part:

To discuss and present to authorities the viewpoints on the care that they presently receive and that they will have.

To provide information for discussion of questions that can be relevant prior to reviewing the law on provisions and services for the retarded. In this way *the* material becomes a preparation for

later discussions about the kinds of suggestions to be made on the revision of the law which the committee will present. These suggestions will also be written in Swedish that is easy to understand.

One problem has been the difficulty of understanding the situation and wishes of those who are not able to express their own will. One suggestion has been that those who are very close to the most severely retarded be able to give their opinions about the needs they believe the person has. One possible form might be to have caretaking staff, teachers and/or family members get together with the retarded for whom they have responsibility and discuss the material in the same way as in other groups.

At the same time, one naturally also assumes that FUB and other organizations who are reporting their reactions to the study are really speaking for the severely retarded as well.

So, what do the retarded living in their own homes have to say about their living situations-most who were asked were mildly retarded, but some moderately retarded were also included. If one takes their own experience of having their own place as the most important measurestick of whether it is good or bad, then it is clear that having their own dwelling is good. It is true however, that several experience social isolation and that especially men have trouble with some of the practical household chores. But like other young people who move from their parents' home to their own place, which perhaps has a lower standard, the retarded experience their own homes positively. The personal experience of independence and personal freedom is decisive and more important than other considerations.

whether they lived in an institution or at home previously, experience their new dwellings positively. The most important reason is the increased personal freedom, the possibility to decide for oneself to a greater degree and to take on responsibility as far as daily life is concerned. Another important experience is not only to be allowed, but also to be able, to take care of oneself, to be able to shop, to fix meals and come on time. Other important things are being able to live in a regular apartment, among other people and not feel so different and apart from others.

Those who lived in institutions previously relate how hampered one was by routines and rules, the feeling of being watched by
226 personnel, how it was to live together with so many other people

the isolated life and the experience of being identified as an idiot when people knew where one lived.

Those who earlier lived with their parents praise the freedom from their parents, and the fact that they can now decide themselves when they wish to meet their relatives, they have freedom of choice.

The study shows that the small group living situation has positively affected **their** self-image, **how** they feel about themselves. The normalized living situation in and not outside of society gives the retarded enhanced self-esteem, they get a more realistic understanding of their capabilities and limits. The integrated group living is experienced as enormously important for themselves.

And the parents. In April and May of this year FUB organized council meetings for their members. In every county, groups of about 5 parents each discussed the situation they and their children face. Each county had at least ten different groups, such as parents to preschool children to students in special elementary and middle schools, to retarded at day care centers, and so forth. Totally almost 300 discussion groups were in action. The conclusions about the dwelling situation were surprisingly unanimous. Preschool and school children should, if possible, live at home. If the parents are unable to take care of the children, then the alternative should be living in other private homes for primarily preschool children, and then group living in groups of four. At the age of twenty the retarded youth should move to his own place or to a group living situation. But, emphasized parents, if one is going to be able to have the retarded child at home without this meaning too much strain on the family, it is almost indispensable that the family get relief. One should be able to have a baby-sitter for the retarded and other eventual siblings some evening a week, one should have a chance to be without the retarded at least one weekend a month and perhaps be able to take some vacation time without the retarded child. Demands for trained home nursing aides as well as small short term apartments with four places in the local towns were presented with amazing sharpness. Likewise parents of retarded adults believe that a ground condition for independent living for the retarded is that they not be left totally on their own, but have access to persons supporting them. As far as boarding houses go, they should really be only small groups in normal living quarters. If what is meant by "boarding
227

house" is a large institution, then, say parents, we would rather have our child at home until we're gone.

There is good reason to pay attention to the parents' demands for supportative measures. That this demand is made with such strength is founded on the fact that parents, according to the councils, find that it is a very difficult, enormous job to have a retarded child at home. This does not by any means mean that people don't love their children. But I had never before seen documented the stress that most people experience in being parents. Perhaps the subject is so delicate that it can only be discussed openly in groups with parents and with anonymously related interviews.

Almost 90% of the responses talk about being tied down, of the physical and psychic strain, of personal privation, of worry that the siblings will be deprived, of the difficulty of accepting the child's retardation, of the problems of operating as a family, of where one does things together, and of older children; briefly, the responses show worry about the future.

Can it be possible that the retarded and their parents, who unfortunately are not seen by everyone as "experts" have managed to misunderstand how the retarded can and ought to live?

Psychologist Gunnar Kylen has recently published a report on the psychological effects of life in an institution, and in connection with this study has gone through a good hundred investigations. All except one show the negative effects of life in care facilities with different degrees of institutional atmosphere, that is to say, large institutions with large living groups, a hierarchically organized structure of responsibility, inflexible care routines, physically or socially isolated, and having untrained personnel without authority.

Emotional life is most disturbed. What is lacking is primarily deep stable emotional contact with one or several persons. Contributing can also be the institutions inflexible milieu as well as the problem of privacy. Several investigations show that lack of emotional stimulation lead to submissiveness and the desperate urge to please on the part of the retarded, they begin to have more difficulties in handling relations with others, tend to become less constructive in their activities, more likely to develop different forms of self-stimulation. This is especially damaging for children and the severely retarded who are most in need of protection.

Several investigations have been made to examine the effect of
228 increased engagement of staff and of life in small groups. In one

large institution, for example, the profoundly retarded were allowed to live for three months in a normal apartment that had been built within the hospital. One group required heavy care, one was apathetic and one was aggressive. All three groups experienced dramatic improvements, demonstrating that even the most severely handicapped can be helped by an improved environment, that they respond to training and can achieve a functional capability which allows elementary social adjustment. Mental development is also hindered in institutional life. Emotional disturbances as well as the less than stimulating environment and isolation from society block usage of the talents the retarded may have. A better environment does not increase intelligence as such but does make possible the employment and development of such talent as are available.

Language is still more dependent upon an emotional ground and a stimulating environment with adults and friends. Language usage is almost always disturbed among retarded in institutions. It has been shown that when retarded move to a normal environment, language usage improves even without special pedagogical training. It has been noted that the severely retarded's communication patterns are disturbed in the same way as the spoken language in the institutional environment.

Self-esteem is also negatively affected by the institutional environment. Self-esteem is not dependent upon intellectual handicaps in themselves, but rather upon the treatment and acceptance one gets. Important contributions to heightened self-esteem are feelings of security and the feeling that one has a will and can take initiatives. Such things are very difficult for an institution to provide.

Thus it seems that research supports the retarded and parents' understanding of how it is best to live. Well one might agree that there is something in all this, but what about groups with special problems? According to Kylen: First, retarded with behavioural disorder. If an aggressive and disturbing person is taken from his home to live in an institution of the larger type is generally found that the disturbing behavior originates in re environment. These people highly need the small integrated group living situation. The few retarded who are incurably disturbed cannot of course be cured by environmental improvements, but they have at least as great a need as others for a stimulating milieu.

The severely retarded often seem to be above and beyond all help. They often have other handicaps in addition to mental retardation.

According to the studies, it is clear that the need for a good environment is as great for the severely retarded as it is for others. The care facility with an institutional atmosphere worsens their handicaps so that they become passive and disturbed and unable to satisfy their needs.

Retarded persons with special needs for medical somatic care, persons who require daily medical attention can need to have access to a nurse, perhaps backed by a doctor. Yet the need for a home-like atmosphere is not made less because of physical illness. And only in a few very difficult cases does the need for medical attention come in conflict with a demand for a good environment.

Those who need intensive care are those who mostly because of various motoric handicaps must be lifted, dressed, fed, changed, and so forth. These persons place special demands on the residence and necessitate increased staff resources. Yet the need for integrated small apartments does not lessen because a person needs intensive care.

The asocial retarded person finally is broken by a care facility with an institutional atmosphere. This only gives them greater handicaps. For this group, as for those with disturbing behavior, the small integrated group in a home is at the core for rehabilitation. In summary I have said:

. That retarded pre-school and school age children should live at home, in another home or in a group home for four.

. That relief measures of different types must be available for families who have retarded children living at home so that they can function well.

.That the retarded should live in normal residential areas and in normal apartments or houses.

.That an integrated residence in small groups is proper even for groups with special problems and that this is a demand made by the retarded and their parents which is backed by unanimous results in research. And finally, it is of enormous importance, although I have not mentioned it previously, that this viewpoint is shared by the responsible authorities in Sweden.

Let us look at two residential models that have been developed in Sweden. One is a model for youth and children, and the other for adults. In both cases it is advantageous to locate groups of dwellings in normal residential neighbourhoods. This in part makes possible social interaction among the retarded, and in part facilitates cooperation among staff members in the individual

residences. By working principally near the home residence of the retarded person, it is possible to have frequent contacts with relatives and others.

These residences should be placed in a way that makes it possible to be functionally integrated into the area, so that the retarded can use public services such as transport, recreation, health care and cultural activities.

The number of retarded should approximate about 1% of the population of the area. Thus in a neighbourhood with 3,000 residents, 30 retarded could be assimilated.

The difference between the various residential units is not the residential form but rather the level and quality of service.

Residential group for children and youth

Dwelling Unit 1-Number of places: 4 per unit-24 hour staffing or daily staffing-sleeping night personnel-walking distance between units-apartments especially suitable for the handicapped.

Dwelling Unit 2-Number of places: 4 per unit-24 hour care-access to medical aid-more staff resources than in type 1-special equipment and design including hygienic facilities-children with need for qualified medical care should be placed in units near to hospitals. In these units there should be access to medical personnel round the clock, and the other, live-in staff personnel-single family home are preferable for this type of residence.

Residential groups for retarded adults

1. Own residence with qualified contact person.
2. Own residence with weekly observation.
3. Group homes with daily attention and help.
4. Group homes with overnight staff.
5. Group homes with qualified attention and care.

Thus, even those retarded persons who can live independently in their own residences can feel secure since they know that they can turn to staff or to someone in the residential group.

In a residential group there should be the above named types of residences. Then the residences could respond to varying degrees of care and need for attention. The retarded then have freedom of choice. Thus, with increased competence and independence, one might have a possibility to move to a more independent kind of dwelling. Or another alternative might be to gradually decrease attention, within the same unit rather than move. In units 4 and 5, there has to be a supervisor, and the

supervisor for one of the units ought additionally to have responsibility for the organization of the whole group.

And now we approach the moment of truth. We who are so clever and progressive in Sweden, we of course have **no** institutions any more. Unfortunately that is not the case, we have a long way to go. Of the children and youth up to the age of 21, 64% live at home, 5% in other private homes, and 15% in group homes. Of our adults, 15% live in homes of their own, and 9% are in group homes. Things are far from ideal yet, but the development is going in the right direction, and even before the next congress in three years, much will have happened.

Perhaps you wonder if the severely retarded are living in group homes today, or whether our ideas are still wishful thinking on that front? In several places we have begun to place severely retarded persons in group homes and the experience has been very positive. Still, however, the majority in boarding situations are those with only mild or moderate retardation.

I have spent a long time on the question "Where to Live" because I am totally convinced that open residences are an absolute necessity for social integration and for seeing that more and more retarded can make demands on their surroundings and give expression to those demands. However, it is not enough merely to have a place to live. To give residence and life meaning there are a number of other conditions. By merely pointing some of them out, I hope to cover the other half of this paper's title: "How to Live?" as well as provide a checklist for this afternoon's discussion.

1. Respect for personal integrity

It is important for every human being, to be treated with personal respect and regard if this person is to develop and learn to adjust socially. This is not a question of strange actions, but rather accepted norms for mutual consideration and interaction-which unfortunately are not always self-evident as far as the retarded are concerned. At the core there is the retarded persons demand to be treated as an independent individual with the principle right to decide for him- or herself.

For example, the retarded must to the highest degree be allowed to decide about their daily activities. Ideas, initiatives, complaints and so on should not be suppressed. Changes in routines must always be motivated and explained.

232 The retarded must also be given a chance to affect their future. If

there is to be a change the retarded should be notified ahead of time and in an understandable fashion. And we can't forget that even when the retarded cannot express themselves in words, there is a body language which can also be highly expressive and communicate with those who know the retarded.

Another thing which I think is very important in this context is the right to one's own room and private life. It just is not right to break into the retarded person's room without knocking-and if no one is being disturbed when he has visitors, then it is nobody's business if the visitor should happen to be of the opposite sex. And since the room is a person's home, it is self-evident that he should give his permission for any visits by study groups and so forth.

Respect of personal integrity, attention to the retarded's own wishes, ambition to meet to the highest degree possible his desires even if it should interfere with one's own personal comfort, to encourage personal initiatives and to have the courage to allow the retarded to try and perhaps fail-these things, I believe, are among the most vital ones if we really want to guide the retarded towards social integration and towards being able to make demands.

This does not mean that we can forget ADL-training. This is necessary if the retarded person is to be able to live as independently as possible, and important for feelings of competence-but it should not be an end in itself, but rather be paired with training in personal development.

2. Training of staff and parents

The key people in open residences are the care-taking staff and the relatives. If they are to be able to stimulate the retarded and see results from both ADL-training as well as personal development-they must receive adequate training. Sufficient and well-trained personnel are necessary to build open residences and to work according to the principle of the small group. In addition it is necessary that care staff have authority equal to their responsibilities-and that both staff and parents increase their influence on the care situation in general.

3. Work and occupation

A national committee recently stated as follows:

If one sees the goal of work as contributing to the development and enrichment of existence and as a way of participating in the community, then it should be the right of all people to have access to work. It is hard to see a definite border beyond which a person's

ability to work is so little that it becomes unimportant for society to solve the problem of employment in its wider meaning.

4. Recreation and leisure

In connection with open residences, the problems of the retarded as to their leisure time have been accentuated. Social isolation and passivity are not uncommon-especially for those in homes of their own. Open residences present entirely different demands on the ability to take initiative. The hopes we have had that the retarded might be able to deal with their leisure by taking advantage of public recreational opportunities have not been answered.

5. Skimpy integration

This was one of Richard Sterner's favorite bugaboos. He continually warned against integration for integration's sake. He underlined the necessity of having supportive personnel for the retarded who lived in their own homes, of having sufficient staff in boarding homes and in services areas, and of seeing to it that parents of the retarded always had a definite person within the care-taking apparatus to whom they could turn with both small and large questions.

I hope that I have been able to convince you that open residences are both good and possible, even for the severely retarded. Additionally I hope, if you have not already done so, that on your return home you set a stop to the construction of new large institutions and try to phase out those already in existence.

I hope your attention has been caught by the debate that Sweden's retarded population is presently having about their situation-a debate which has as an aim that the retarded themselves begin to make demands.

And as a final note to my contribution, allow me to communicate a demand from the retarded people of Sweden, which reads as follows: We expect that we will be allowed to actively take part in the 8th World Congress of the International League of Societies for the Mentally Handicapped. And we expect an invitation well in advance.